

Coping With Stigma by Association and Family Burden Among Family Members of People With Mental Illness

Citation for published version (APA):

van der Sanden, R. L. M., Stutterheim, S. E., Pryor, J. B., Kok, G., & Bos, A. E. R. (2014). Coping With Stigma by Association and Family Burden Among Family Members of People With Mental Illness. *Journal of Nervous and Mental Disease*, 202(10), 710-717. <https://doi.org/10.1097/NMD.0000000000000189>

Document status and date:

Published: 01/10/2014

DOI:

[10.1097/NMD.0000000000000189](https://doi.org/10.1097/NMD.0000000000000189)

Document Version:

Accepted author manuscript (Peer reviewed / editorial board version)

Document license:

CC BY-NC-ND

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy

If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.



Coping with stigma by association and family burden among family members of people with mental illness

Remko L.M. van der Sanden¹, Sarah E. Stutterheim²,
John B. Pryor³, Gerjo Kok¹ and Arjan E.R. Bos²

1 Maastricht University, Maastricht, the Netherlands

2 Open University, Heerlen, the Netherlands

3 Illinois State University, Normal, USA

Published as:

van der Sanden, Remko L.M. MSc^{*}; Stutterheim, Sarah E. PhD[†]; Pryor, John B. PhD[†]; Kok, Gerjo PhD^{*}; Bos, Arjan E.R. PhD[†], 2014

Coping With Stigma by Association and Family Burden Among Family Members of People With Mental Illness. *The Journal of Nervous and Mental Disease*, 202, 10, 710-717

Coping with stigma by association and family burden among family members of people with mental illness

Remko L.M. van der Sanden¹, Sarah E. Stutterheim², John B. Pryor³, Gerjo Kok¹ and Arjan E.R. Bos²

¹ Maastricht University, Maastricht, the Netherlands

² Open University, Heerlen, the Netherlands

³ Illinois State University, Normal, USA

In this study we explored stigma by association, family burden, and their impact on the family members of people with mental illness. We also studied the ways in which family members coped with these phenomena. We conducted semi-structured interviews with twenty-three immediate family members of people with mental illness. Participants reported various experiences of stigma by association and family burden. Social exclusion, being blamed, not being taken seriously, time consuming caregiving activities, and exhaustion appeared to be the predominant forms of stigma by association and family burden experienced by participants. Participants used problem-focused and emotion-focused coping strategies, separately or simultaneously, to cope with the negative impact of stigma by association and family burden. The results suggest family members should have access to services to address these problems. Social, instrumental and emotional support should be given to family members by community members and mental health professionals.

Introduction

People with mental illness are confronted with stigma regularly. They have been discriminated against in several ways throughout the centuries and public images of people with mental illness still tend to be very negative (González-Torres, Oraa, Arístegui, Fernández-Rivas, & Guimon, 2007). People with mental illness are often seen as being deviant, dangerous, and less competent than others (Wahl, 1995). The stigma associated with mental illness is known to have a tremendous impact on the daily life and the life satisfaction of people with mental illness; it also contributes to unemployment and low income among them (Markowitz, 1998). Furthermore, people with mental illness often experience a reduction in social contact and an increase in social rejection, which may lead to social isolation and diminished self-esteem (Bos, Kanner, Muris, Janssen, & Mayer 2009).

Most family members of people with mental illness who have participated in relevant surveys and research in the Netherlands have contact with their family member with mental illness at least once a week. They have regular contact in person, by phone, or by e-mail. Some of them see each other daily and many are involved in caregiving activities for their family member with mental illness (Van Erp, Place, & Michon, 2009). They usually support their family members practically, helping with housing, food and money as well as giving emotional support. Family members of people with mental illness in the Netherlands reported positive as well as negative effects of their family member's mental illness (Kwekkeboom, 2000). They learned to accept their family member's deviant behaviour and felt themselves appreciated for their caregiving activities, yet 75% reported regularly being irritated by his or her behaviour, tensions within the family, or disruption to their life because of their family relationship with a person with mental illness (Kwekkeboom, 2000). It has been shown that

the stigma of mental illness not only affects people with mental illness but their family members as well by the mere association to them. This phenomenon is called stigma by association (Neuberg, Smith, Hoffman, & Russell, 1994; Östman, & Kjellin, 2002; Pryor, Reeder, & Monroe, 2012). Family members of people with mental illness who had experienced stigma by association reported stress and anxiety, a reduction in social interactions, social exclusion, and negative treatment. As a result of these experiences some of them devoted energy and resources to concealing their relationship to the family member with mental illness (Larson & Corrigan, 2008; Van der Sanden, Bos, Stutterheim, Kok, & Pryor, 2013). The behaviour of a person with mental illness may further isolate his or her family, diminish their reputation, and jeopardise their relationships with friends and neighbours (González-Torres et al., 2007).

Family members of a person with mental illness also have to deal with family burden (Farina, Fischer, & Fischer, 1992; Judge, 1994). Platt (1985) presented one of the first definitions of burden, this definition referred to difficulties, problems, and adverse events affecting people with mental illness and their families (Schene, 1990). Although the term 'burden' is sometimes perceived as a stigmatising term is its use in research to refer to "all the difficulties and challenges experienced by families as a consequence of someone's illness" (Ennis & Bunting, 2013, p. 255) well known, it is in this sense that it is used in this study. Several researchers argued that family burden was a multidimensional concept as the problems and challenges which may be experienced by family members of someone with a mental illness include financial hardships, time consuming caregiving activities, disruption of normal household routines and roles, and psychological distress related to the illness of this family member (Schene, 1990). Family burden is frequently categorised descriptively as objective burden or subjective burden. Objective burden includes the factual negative impact and problems experienced by the family of a person with mental illness as a result of the mental illness. Subjective burden includes the negative emotional impact on the family of a person with mental illness, and the psychological distress caused by his or her mental illness (Tsang, Tam, Chan, & Chang, 2003).

Several researchers have classed stigmatisation as a dimension of subjective burden or described stigmatisation as a psychosocial burden (De Boer, Mula, & Sander, 2008; Sales, 2002; Schene, Tessler, & Gamache, 1996). Werner, Mittelman, Goldstein, and Heinik (2012) even reported that stigma by association was a significant predictor of family burden, "above and beyond the influence of more traditional predictors" (p. 91). Nevertheless, there are other definitions and indices of family burden that do not refer to stigmatisation or stigma by association. We therefore suggest that although stigma by association may be related to family burden and their consequences may overlap to a certain extent, the two constructs are not identical. Most importantly, the overlap between the impact of stigma by association and family burden seems to depend on the definitions and operationalisation of the concepts.

Nonetheless, experiences of being stigmatised and the burden of a family member's mental illness do threaten the physical, psychological, emotional and functional health of the family of a person with mental illness (Angermeyer, Schulze, & Dietrich, 2003; Phelan, Bromet & Link, 1998). Experiences of being stigmatised affects their levels of self-esteem, stress and anxiety, and their social performance (Rüsch et al., 2009); these are important issues in psychiatric rehabilitation because they affect both the recovery of the person with mental illness and their family. Stigma by

association and burden are major stressors for the family of a person with mental illness and may lead to use of a variety of coping strategies to mitigate their negative impact (Carver, 1997; Miller & Kaiser, 2001). Coping strategies are often categorised into problem-focused coping strategies (i.e., use of instrumental support, use of emotional support, active coping, planning, and use of humour) and emotion-focused coping strategies (i.e., venting, self-blame, acceptance, substance use, behavioural disengagement, denial, self-distraction, positive reframing, and religion) (Carver, Scheier, & Weintraub, 1989; Eaton, Davis, Hammond, Condon, & McGee, 2011; Stutterheim, 2011). Problem-focused coping strategies are intended to reduce or eliminate the negative impact of a stressor and facilitate recovery of function, whereas emotion-focused coping strategies are focused on managing the negative emotions associated with the stressor (Carver, 1997; Eaton et al., 2011; Tuncay, Musabak, Gok, & Kutlu, 2008). Lazarus and Folkman (1984) found that participants' appraisal of a stressor strongly predicted the coping strategies they would use. If the stressor was perceived to be relatively manageable or controllable it was more likely that participants would use problem-focused coping strategies; if they perceived the stressor to be relatively unmanageable or uncontrollable they were more likely to choose emotion-focused coping strategies.

However, stigma by association, family burden, and the ways family members of people with mental illness cope with them have not yet been studied extensively. In this qualitative study the experiences of stigma by association and the burden on the immediate family of people with mental illness were investigated in more detail. We also explored how family members coped with stigmatisation and burden as this may improve our understanding of how experiences of stigma by association and family burden affect the family of a person with mental illness and suggest possible interventions aimed at reducing their negative impact.

Method

Participants and Procedure

This qualitative study explored experiences of stigma by association and burden among members of the immediate family (i.e., parent, child, sibling or spouse) of people with mental illness. The Research Ethics Board of the School of Psychology and Neuroscience at Maastricht University approved the study.

Between March 2012 and April 2013, 23 members of the immediate family of a person with mental illness participated in face-to-face, semi-structured interviews. All participants were Dutch Caucasian men (11) or women (12). Their ages ranged from 25 to 64 years, with a mean age of 44.3 years ($SD = 12.6$). Participants' characteristics are shown in Table 1. The types of mental illness reported varied, depressive, bipolar or other mood disorder: 12 persons; personality disorder: 4; Attention Deficit Hyperactivity Disorder or Attention Deficit Disorder: 4; dissociative disorder: 3; autism: 3; schizophrenia or other psychotic disorder: 2; addiction: 1. At the time of interview, 12 participants were in contact with the family member with mental illness on a daily or weekly basis, 8 did not have regular contact with that family member (i.e., contact approximately four or fewer times a year) and in 3 cases the family member with mental illness had deceased. Participants were recruited through announcements distributed by Dutch mental health institutes and mental health self-help groups (e.g., Labyrint-in-Perspectief, Vereniging Geestdrift, Zorgbelang Brabant, Stichting Borderline,

Stichting Caleidoscoop); 4 participants were recruited directly by the first author. After recruitment participants were given further information about the purpose and procedures of the study. Informed consent was obtained from all participants prior to interview. All participants were interviewed for approximately 1.5 hours at a location deemed appropriate by participant. Interviews continued until theme saturation was achieved. To improve the rigour of the research all interviews were recorded with a Dictaphone and transcribed verbatim.

Table 1 Demographic and Background Characteristics of Sample (N=23)

Variable	Percentage (%)
Gender	
Male	47.8
Female	52.2
Age	
Years (mean (SD))	44.3 (12.6)
Range (min-max)	25 - 64
Marital status	
Single	13.1
Married	52.1
Divorced	21.7
Widowed	13.1
Family relationship	
Spouse	20.7
Child	20.7
Parent	27.5
Sibling	31.1

The interviews themselves were guided by a structured protocol consisting of open-ended questions and follow-up probes. The protocol explored participants' experiences of stigma by association and burden, including the extent to which stigma by association and burden affected the participant's life and well-being, and the ways in which the participant coped with these experiences. The questions put to the participants in this study were divided among the introductory part of the interview and six main themes:

1. their family, the mental illness of the relevant family member, and their relationship with this family member;.
2. their experiences of stigmatisation of people with mental illness.
3. their experiences of stigmatisation of the family of people with mental illness.
4. burdens they experienced as a family member of a person with mental illness.
5. their coping strategies and the perceived effectiveness of these strategies.
6. further themes, items and questions participants thought were relevant to our research.

The questions and follow-up probes in a pilot protocol were developed from current literature, previously used protocols and validated scales for assessing the experiences and consequences of stigma by association, burden and coping (e.g., Mental Health Inventory, Veit & Ware, 1983; brief COPE scale, Carver, 1997; Stigma-by-association scale, Pryor et al., 2012; Burden scale, Pryor et al., 2012; Interview protocol, Stutterheim, 2011). The questions and themes in this pilot version of the protocol were presented to several professionals, peers, people who had a family member with mental illness, and people with mental illness and adjustments were made to the protocol and topic guide based on their input. Next, the protocol questions and follow-up probes was tested in pilot

interviews with three persons who had a family member with mental illness. Their remarks and input prompted further adjustments to the protocol. During these pilot interviews participants were explicitly invited to give their opinion on the research questions and asked if the interview had missed essential questions or themes, thus our protocol evolved and was enriched through partnership with participants.

To manage and analyse the data, the interview transcriptions were imported into a computer software package for qualitative data analysis (QSR NVivo 9.0). Data were processed and analysed using a general inductive approach and thematic content analysis (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008; Thomas, 2006). The first author undertook 'open coding' and examined recordings and transcripts thoroughly to identify relevant subjects. Subsequently, researchers started describing, analysing, organising, and categorising variations on themes and concepts by identifying similarities and differences in the data. Themes and concepts were then further investigated and a node structure (i.e., hierarchical data structure) based on these themes and concepts was developed (Bazeley, 2007; Polit & Beck, 2010). The creation of the hierarchical data structure with nodes, child nodes, leaf nodes and attributes was subject to regular discussion, consultation and review among the researchers and evolved into a concerted node structure. This node structure accounted for all our data. Changes to the hierarchical data structure and the reasons for such changes were logged. The decision trail was recorded in the same log (Burnard, 2004; Polit & Beck, 2010).

Results

Experiences of stigma by association

The themes encompassing topics and dimensions that emerged prominently in the interviews in this qualitative study are presented in a summary table (Table 2). Seventy-four percent of the participants in this qualitative study reported experiences of stigma by association. They described how these stigmatising reactions affected their mental wellbeing, social life and social networks: "They [other community members] tried really hard to find something. It felt like there had to be something to find, there had to be something wrong with you." (Jennifer, sister, age 45 years).

An issue frequently mentioned by participants was changes in family relationships and friendships over time, sometimes the relationship or friendship even broke up: *Actually I get on well with my nieces and nephews, with my family, but there are some things which the family won't mention to anyone, not even to aunts and uncles. Mental illness wasn't acceptable. No, it didn't fit the image, oh, no! In any case, it's a taboo, and creates distance between us* (Carmen, mother, age 58 years).

Several participants reported avoiding social events and reducing or breaking contact with family, friends and acquaintances because they did not want to be confronted with awkward questions and remarks about their family member with a mental illness or their family anymore: "I often had that [avoiding social events]. You know, that I had to go somewhere, but I just stayed at home, avoided difficult situations. You realise your world is getting smaller." (Rachell, mother, age 59 years); "I think you're subconsciously aware of it [that some people think you're bringing up your child wrongly] and so you already have your story ready. You've heard it all before of course." (Cally, mother, age 59 years). Members of the family of a person with mental illness also feared stigmatising reactions and

the potential loss of relationships and friendships when it came to potential partners: *It's not really a problem, but of course it's never easy and I still come up against it sometimes. So you have something like, for example, I've got a girlfriend, should I tell her... I've been going out with her for 3 or 4 months... but she's never met my mother. And I do have a particular reason, for, like, putting it off as long as possible. And that, oh I don't know, feeling embarrassed, it's just the idea, I don't know actually. Let her get to know me first and if she likes me enough, then it won't make any difference any more (John, son, age 25 years).*

Negative treatment and exclusion were also commonly reported experiences of stigma by association. A number of participants noted that teenage and adolescent family members of people with mental illness experience explicit stigmatisation and negative treatment because of their association with a stigmatised person: "Then I thought, well for goodness sake, he's the one with the problem and now I have to go to the psychologist [with him]. Especially because other people were judging and teasing me for it." (Mike, brother, age 29 years). Several participants felt themselves stigmatised by mental health professionals too: *So I had to go on one of those visits to the psychologist or psychiatrist. I went more for my parents than for my sister because I couldn't do anything to help her anyway. So I went there, but I hated it. They started off by commenting on where we sat down, that my parents were very protective, and you had to talk about all sorts of personal things that you wouldn't normally talk about. I absolutely hated that and that's one of the reasons that I'm not letting my children take part in all sorts of national health studies and things like that. Ugh, I never went back again, (Jennifer, sister, age 45 years).*

Some family members of people with mental illness recalled stigmatisation which took the form of being blamed for the onset or continuation of the mental illness of their family member: "My parents didn't know anything about it [*mental illnesses*]. They're from another generation. They were like, do you mean to say that we...[*caused our grandson's mental health problems*]. Yes, we felt ashamed too. Acceptance is a process." (Chris, father, age 47, years).

Lastly, several participants explained that direct burdens and day-to-day problems which occurred during mental health crises pushed their experiences of stigma by association into the background "No, people definitely don't understand and there have been a few major rows about it [*verbal stigmatisation*]. I used to think, mind your own business, and I'd say it out loud later, but I'd had enough. At the time I had other things to worry about" (Ken, husband, age 54 years).

Burden

Eighty-seven percent of the participants in this qualitative study also reported experiencing family burden.

Objective burden

Participants who had a family member with mental illness reported concrete problems and the effects these had on the family's household routine and everyday tasks, as well as other concrete ways in which their life was disrupted. Quarrels and tussles were reported frequently: *My mother was really upset that we argued so often at home, that we as siblings sometimes wanted him to go*

away and sometimes hit him. And then she was angry with us and that upset me, but, at the same time, I thought if he'd just act normally, then we wouldn't have to react like that (Brita, sister, age 30 years).

A few participants also experienced financial hardship. In some cases the family member with mental illness had not been able to manage his or her finances and had incurred debts that he or she could not pay back. Participants supported this member of the family financially and were expected to cope with the financial and judicial problems at the same time: *"Now we're trying to clear up the mess again, financial mess too because there are three debt collectors on the doorstep. It's taking months. It wears you out."* (Yasmina, mother, age 59 years). Occupational limitations, missed career opportunities, and consequently financial hardship sometimes, were occasionally mentioned by participants. One of them said that his wife had to stop working because of their son's illness: *"My wife was a teacher and we reached the point where we decided she'd have to stay at home [and give up her job] and take care of him"* (Bill, father, age 58 years).

Subjective burden

Participants spoke with great emotional intensity about the subjective burden their family member's mental illness had placed on them and the psychological distress engendered by being a family member of someone with mental illness. Having a family member with a mental illness was also very time consuming for most participants and they reported that it could lead to feelings of exhaustion: *"Always making excuses, more excuses, always talking your way out of things, that's what you have to do. And never being able to rest, always being on the edge of my seat; even now, always ready for action, always alert."* (Frieda, spouse, age 61 years), similarly: *You can't really manage the instability. You can't really live with it. Constantly asking if it's all right but making a point of never asking how they really feel, is exhausting. So in that sense it has taken its toll on me, on my energy and on my enjoyment of life. You're dealing with it almost 24 hours a day, even if you're not dealing with it* (Lenny, spouse, age 45 years).

Some siblings and parents noticed that the mental illness of a family member was not only time consuming, but also led to the other children in the household receiving less attention, and that this change or disruption of family relationships sometimes led to feelings of guilt and anger. One participant explained that she felt forlorn because of the attention given to her sister with mental illness: *As a sister, you've got your own life, but suddenly nobody pays any attention to what you're doing anymore, because that's all going well. All the attention is focused on one problem, her illness, and you're not involved in it anymore and then you no longer have any real contact with your family [sigh]. You sort of accept it, but you're really always an afterthought* (Jennifer, sister, age 45 years).

Another participant mentioned that he and his wife suddenly noticed that their attention was almost exclusively focused on the son who had a mental illness and that this was affecting their other two sons negatively: *There was a time that he [the son with a mental illness] was the only thing we could talk about. Everything revolved around that, everything. Suddenly I realised that the other two boys just weren't getting enough attention. That's a dangerous situation; everything was centred on him. His name came up in every sentence, even when the other boys asked me something; then I referred to his name in my answer. So they began to rebel against it. We should have recorded it and listened*

to it in the evening. We would have been thoroughly ashamed of ourselves. (Chris, father, age 47 years).

Finally, feelings of helplessness and loneliness were also common among participants: *"It's really tough, and you feel really isolated, even from the people around you. You think that nobody understands you anymore, but it isn't possible for people to understand, I realise that now."* (Frieda, spouse, age 61 years).

Coping

In an effort to mitigate the effects of stigma by association and family burden, family members of people with mental illness used various problem- and emotion-focused coping strategies (Carver, 1997; Miller & Major, 2000). Sometimes, family members used just a single coping strategy, but most used several coping strategies simultaneously.

Problem-focused coping

Many participants in our study reported using problem-focused coping strategies, and a number of them mentioned using selective disclosure as an active coping strategy to prevent stigma by association and its negative impact: *"Being too open isn't good either, but I do think functional openness is important."* (Jessica, mother, age 58 years), *"After all, you do have to explain that it's not going so well and why you're not working so well. So, I did want to do something to create understanding and as a sort of explanation of why I can't cope for a while."* (Lenny, spouse, age 45 years).

Coping strategies whereby participants tried to get emotional support, understanding, or empathy were reported frequently too: *"You can discuss how it makes you feel, if you need help or something, if you need information, I don't know, do you need someone to listen?"* (Frieda, spouse, age 61 years). The use of instrumental support, for example information, help, practical support in daily life and advice about what to do, was also regularly used as a coping strategy: *I think that parents have to get help and you can't do it all on your own. You have to follow the same rules and if you can't, for God's sake get some help or you'll end up getting divorced. You need to talk to somebody sometimes, with experts so that you really know what's going on. Professionals have to help people to look at the situation and work out how they can deal with it together.* (Bill, father, age 58 years)

In addition, several participants started organising support systems: *"Of course, I had to build up a support system because I had a job and all sorts of responsibilities"* (Linn, mother, age 57 years), *"[asked how he coped] Build up a network so that other people can take over responsibility, can take your place, can replace you."* (Lenny, spouse, age 45 years).

Emotion-focused coping

Family members of people with mental illness used emotion-focused coping strategies as well as problem-focused coping strategies. Denial, behavioural disengagement, self-distraction, acceptance, and venting were reported by participants.

'Accepting that the mental illness was real, stigmatisation did occur and one had to accept and handle the stigma', was mentioned as a strategy for diminishing the impact of stigma by association and its associated psychological distress as well: "Acceptance is number one; you have to accept it. You can't change it anyway because that's not going to happen. You shouldn't make it too much your own problem." (John, son, age 25 years) and "Now he's been diagnosed, I can understand things better, it gives me more peace. I think because I can accept it more easily when he's slow sometimes now." (Linn, mother, age 57 years).

Participants described in detail how they used activities in an attempt to distract themselves from the stigmatising family situation. Frequently mentioned opportunities for distraction were going out and participants' workplaces: "There's not a good environment at home, so you have to create a comfortable feeling for yourself, you have to make something of it yourself. I found it at work, going out, with my friends." (Jennifer, sister, age 45 years), "Work kept me going all that time. It was like my comfort blanket. I'd rather go to work than to the supermarket where you see everyone you know and they avoid you like the plague." (Frieda, spouse, age 61 years) and "I could relax at work and honestly, there's nothing worse than people who can only relax at work. That means their home environment isn't a safe haven anymore" (Ken, spouse, age 54 years).

Denial and rejection of the reality of the stigmatising situation were other tactics used by participants: "We had a period when we ignored everything, we were in denial, a bit like keeping it secret, and then, if you went out, don't talk about it!" (Chris, father, age 47 years). Several participants who had a family member with mental illness gave up on attempts to cope with stigma by association and its consequences. This approach was based mainly on behavioural disengagement: "I'm very down-to-earth about it. It's not my problem, so I distance myself from it. You place the problem clearly with him or her, not my problem." (John, son, age 25 years). Participants also reported avoiding situations in which they were likely to be expected to talk about their family member's mental health condition: "You don't go to parties anymore, you don't go outside with her, you only go out to do the shopping. Actually, you make it so that she becomes isolated too." (Ken, spouse, age 54 years).

Lastly, some participants indicated that they coped with stigma by association and burden by venting their emotions and discharging their feelings of emotional distress:

So then, I had an appointment with a psychiatrist. He didn't have to say anything, I tell you, I talked for an hour and a half and I was so angry and said to his face, 'You just sit there and I'll do the talking' and in an hour and a half, I let it all out and said 'I never want to see you again.' That's what I did. I spent an hour and a half ranting, crying and sobbing, swearing, talking, and then I left, and I've never seen him since. (Frieda, spouse, age 61 years).

Humour, religion, positive reframing, and substance use were indicated as possible coping strategies in earlier studies (Carver, 1997), but these coping strategies were not explicitly reported by participants in our study.

Contact

Most family members in this study kept in regular contact with the member of their family who had a mental illness. They were in contact in person, by phone, or e-mail (Van Erp et al., 2009), typically on a daily or weekly basis. However, some participants acknowledged they had little contact with that family member. They stated this was primarily a consequence of that family member's previous or current behaviour, or because of quarrels and tussles they have had with that family member. Two participants reported that they did not want to be associated with that family member anymore because of his or her behaviour, illness or its stigmatising effect; they had withdrawn almost entirely from the relationship and minimised contact.

Table 2: Themes Emerging From Interviews

Topics prominent in interview	Dimension involved	Frequency in sample (N = 23)
	n	%
Stigma by association	17	74
Not being taken seriously	9	40
Being avoided	8	35
Negative treatment	5	22
Social exclusion	6	26
Perceived as strange	5	22
Blamed /made to feel guilty	8	35
An object of pity	2	8
Accused of over-protectiveness	8	35
Burden	20	87
Financial	7	30
Loneliness	8	35
Exhaustion	7	30
Stress and irritation	17	74
Time consuming	9	40
Divorce	6	26
Had to move	6	26
Missed career opportunities	5	22
Family relationships are less close and caring	9	40
Legal action	7	30
Quarrels and tussles	12	52
Coping	23	100
Sharing	6	26
Therapy	13	56
Advocacy and support groups	17	74
Support	5	22
Self-control	6	26
Concealment	1	4
Plan or structure	8	35
Withdrawal	15	65
Distraction	7	30

Acceptance	6	26
Abandonment	4	17
Conflict	5	22

Discussion

Participants in this study reported a range of forms of stigma by association including negative treatment, not being taken seriously, being blamed, social exclusion and alterations in family relationships and friendships. These experiences of stigma by association are similar to those reported by Lefley (1989) who found that stigma transferred from people with mental illness to their family, resulting in the erection of social barriers, isolation of the family and a diminishing of its reputation, and jeopardising social relationships with family, friends and neighbours. Some participants noticed that they reduced the size of their social network and avoided social events because they could no longer handle the distress caused by being confronted with stigmatising behaviour and remarks directed against them or their family member with mental illness. These findings are in line with those of Tsang et al. (2003) who noticed that some family members of people with mental illness avoided social events and sacrificed social relationships to conceal the mental illness of a family member. Some participants mentioned being blamed for the onset or continuation of a family member's mental illness as a specific example of stigma by association. This is in accordance with Corrigan and Miller (2004), who found that family members of a person with mental illness were blamed for the onset of that person's mental illness, held responsible for relapses, and socially excluded as a result.

Participants also described various manifestations of family burden including quarrels, financial hardship and missed career opportunities. Participants mentioned that taking care of a person with mental illness was very time consuming too. Similar burdens (e.g., social isolation, time consuming activities, financial hardship, altered family relationships and disruptions of household functioning) were found among family members of people with mental illness by Tsang et al. (2003) and Lefley (1989).

It was not usually possible for participants to determinate exactly which part of the negative impact (e.g., psychological distress, diminished quality of life) was related to stigma by association and which to family burden; most of the time a combination of the two appeared to be involved. Participants also reported that during a mental health crisis they focused on surviving and handling the crisis and associated burdens and paid much less attention to coping with experiences of stigma by association. During these crises the direct burden and day-to-day problems had to be handled and this appeared to push stigma by association into the background. It seemed that during a crisis participants could no longer deal with all experiences, problems and burdens simultaneously and had to prioritise. However, mental health crises can vary substantially in type and severity and therefore participants' experiences and reactions during these crises may vary across crises as well as individuals.

Participants used both problem-focused coping strategies and emotion-focused coping strategies to diminish the negative impact of stigma by association and family burden. This is in line with the findings of Eaton et al. (2011) who reported that some family members of people with mental illness used emotion-focused, avoidance-based coping strategies when they had to deal with the stressor

and its consequences, whereas others used problem-focused coping strategies and made efforts to reduce the frequency or intensity of the stressor and manage its impact. Problem-focused coping strategies used by participants in our research were mostly aimed at obtaining social, instrumental or emotional support. The most frequently used problem-focused coping strategies reported by participants were selective disclosure, organising support systems, trying to get empathy, talking to professionals and asking for professional support. Organising support systems was the main factor referred to when discussing active handling of the burdensome family situation. Selective disclosure was also used as an active coping strategy by participants, as a way of creating understanding and increasing support. This finding is similar to Bos et al. (2009), who found selective disclosure was used by mental health service users as a way of generating social support and diminishing stigmatisation. Emotion-focused coping strategies used by participants seemed to be aimed at evading or distancing oneself from stigmatising conditions and burden. Specific emotion-focused coping strategies reported by participants included accepting a stigmatising situation, disengaging or withdrawing from the family member with mental illness or from the stigmatising situation, venting, distracting themselves by going out, taking refuge in work, or visiting friends. Participants, especially spouses, noticed that taking refuge in work as a form of self-distraction was an important signal that things were going wrong at home; however this also seemed to be a generally accepted way of coping, and was seen as an easy way out of the stigmatising and burdensome family situation. Emotion-focused coping strategies seemed, at least some of the time, to reduce the intensity of negative and distressing emotions resulting from stigma by association and family burden. This is in line with the findings of Clarke and Tanya (2009) who reported that short-term stress reduction and improvements in patients' quality of life were more strongly associated with emotion-focused coping strategies, whereas problem-focused coping strategies were associated with longer-term improvement. Participants in our study seemed to use both types of strategy separately and simultaneously at different points, a finding in line with Stutterheim's (2011) report that HIV-positive participants combined several coping strategies to mitigate the negative impact of stigmatisation.

During interviews, several participants drew attention to the specific challenges faced by siblings of people with mental illness, stating that siblings generally had or felt less responsibility for caregiving and rehabilitation of the person with mental illness than did parents or spouses. This is consistent with the findings of Seeman (2013), who reported that siblings of patients with schizophrenia were an important component of the patient's social network, but mostly did not take an active part in caregiving until their parents could no longer cope alone. Our participants also reported that most people with mental illness claimed a lot of attention at the expense of their siblings. Some siblings in our study found this extremely disruptive to family relationships and household functioning. Lefley (1989) reported similarly that the attentional focus on people with mental illness, together with the time spent on caregiving, often led to neglect of other family members. Several siblings in our study found taking part in family therapy stigmatising and burdensome. In particular, talking about personal feelings and thoughts in the presence of their parents or to 'complete strangers' (i.e., mental health professionals) was especially challenging for some siblings during puberty and adolescence. Some of them felt forced to do so and this caused shame and anger. They may have felt themselves stigmatised by their siblings' mental illness and this could have had a negative effect on their involvement in the treatment processes and family therapy. Consequently, we found that the risk of losing siblings' involvement and support within the household of people with mental illness is not imaginary (Corrigan et al., 2004; Seeman, 2013). Good communication within the family,

attention to siblings' emotions and personal needs, clear expectations and family roles may be needed to keep siblings involved in the family situation and supportive of therapy. Specific attention should be paid the loss, grief, frustration, loneliness, shame and anger associated with having a sibling with mental illness (Ewertzon, Cronqvist, Lützén, & Andershed, 2012). Mental health professionals and parents should invite siblings to special events and psycho-educational group discussions on a strictly voluntary basis and develop these events in partnership with the siblings of people with mental illness.

Study strengths and limitations

Our study has both strengths and limitations. Most importantly, this study is among the first to examine stigma by association, family burden, and coping strategies together. The rigour of our study is another strength; we ensured research quality, reliability, and validity by using a semi-structured protocol consisting of open-ended questions and follow-up probes to structure interviews. The involvement of people with mental illness and their family members in the development of the interview protocol enriching the protocol through partnership was another strength of this study. Lastly, the rigour of our study was further improved by using digital voice recorders and verbatim transcription to construct extensive 'thick' descriptions, recording the decision trail transparently throughout the data analysis process and using proven, validated qualitative data analysis software.

However, some limitations to our study must also be mentioned. Caution should be applied in generalising the results to other populations because this was qualitative research. Another limitation is that most participants were recruited via self-help and support groups which may have resulted in a sample biased towards highly involved individuals. Participants in our study may have been better equipped than most family of people with mental illness to cope with experiences of stigma by association because most were receiving support from mental health professionals; this study may therefore have underestimated stigma by association and its wider impact. The open coding in this study was mainly done by the first author; while inter-rater reliability could have enhanced the rigour of the study. Lastly, participants reported not only their present but also their past experiences; their recollection of past and present emotions may not have been accurate and their interpretation of past events and experiences may have changed over time.

Conclusion and implications

We have found that participants suffer as a result of stigma by association and family burden. Social exclusion, time consuming caregiving activities, being blamed, not being taken serious and exhaustion were conspicuous features of stigma by association and burden for the family members of people with mental illness. Participants in our study used problem-focused and emotion-focused coping strategies to cope with their experiences of stigma by association and burden. They used both types of strategy in combination and separately. However, during mental health crises participants seemed to concentrate almost exclusively on dealing with the immediate burden of the situation, rather than worrying about stigma by association. Lastly, it appears that siblings need specific attention if they are to remain involved with and supportive of their family, particularly during puberty and adolescence. Our findings suggest that services should be provided for the families of people with mental illness to address these problems. When one is confronted with stress that

exceeds one's ability to cope, for example the onset or relapse of a family member's mental illness, other family members and mental health professionals should provide emotional support and assist with coping strategies to enable one to deal with the new family situation. Social support and the efforts of participants to help their family members with mental illness should also be recognised, acknowledged and reinforced by extended family members, community members and mental health professionals. There should also be services and facilities to provide respite from caring for a family member with mental illness. Lastly, particular attention should be paid to the personal needs and emotions of siblings of people with mental illness, they should be encouraged to attend psycho-educational group discussions and events by self-help groups, although attendance should be on a voluntary basis. We recommend that future research investigate the relationships among family roles, stigma by association, family burden, and coping more extensively. We advocate future research to include younger family members, aged between 12 and 18 years. We further recommend community-based participatory research into the specific relationships involving stigma by association, family burden, and their impact. Such research should be done through a strong, carefully considered partnership between researchers and the families of people with mental illness. Lastly, we suggest further quantitative research to focus specifically at the distinction between stigma by association and family burden, and potential differences between strategies used to cope with stigma by association and family burden.

References

- Angermeyer, M. C., Schulze, B., & Dietrich, S. (2003). Courtesy stigma: A focus group study of relatives of schizophrenia patients. *Social Psychiatry Psychiatric Epidemiology*, 38, 593-602.
- Bazeley, P. (2007). *Qualitative data analysis with NVivo*. (pp. 6-15) London: Sage Publications Ltd.
- Bos, A. E. R., Kanner, D., Muris, P., Janssen, B., & Mayer, B. (2009). Mental Illness Stigma and Disclosure: Consequences of Coming out of the Closet. *Issues in Mental Health Nursing*, 30, 509-513.
- Burnard, P. (2004). A method of analysing interview transcripts in qualitative research. *Nurse Education Today*, 11(6), 461-466.
- Burnard, P., Gill, P., Stewart, E., Treasure, K., & Chadwick, B. (2008). Analysing and presenting qualitative data. *British Dental Journal*, 204, 429-432.
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the brief COPE. *International journal of Behavioral Medicine*, 4, 92-100.
- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56(2), 267-283.
- Clarke, D., & Tanya, G. (2009). The mediating effects of coping strategies in the relationship between automatic negative thoughts and depression in a clinical sample of diabetes patients. *Personality and Individual Differences*, 46(4), 460-464.
- Corrigan, P. W., & Miler, F. E. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health*, 13(6), 537-548.
- De Boer, H. M., Mula, M., & Sander, J. W. (2008). The global burden and stigma of epilepsy. *Epilepsy and Behavior* 12(4), 540-6.
- Eaton, P. M., Davis, B. L., Hammond, P. V., Condon, E. H., & McGee, Z. T. (2009). Coping Strategies of Family Members of Hospitalized Psychiatric Patients. *Nursing Research and Practice*, 2011, 1-12.
- Ennis, E., & Bunting, B. P. (2013). Family burden, family health and personal mental health. *BMC Public Health*, 13, 255.
- Ewertzon, M., Cronqvist, A., Lutzen, K., & Andershed, B. (2012). A Lonely Life Journey Bordered with Struggle: Being a Sibling of an Individual with Psychosis. *Issues in Mental Health Nursing*, 33, 157-164.
- Farina, A., Fischer, J. D., & Fischer, E. H. (1992). Societal Factors in the Problems Faced by Deinstitutionalized Psychiatric Patients, In P. J. Fink & A. Tasman (Eds.), *Stigma and mental illness* (pp. 167-184). Washington, DC: American Psychiatric Press.

González-Torres, M.A., Oraa, R., Arístegui, M., Fernández-Rivas, A., & Guimon, J. (2007). Stigma and Discrimination towards People with Schizophrenia and their Family Members; a Qualitative Study with Focus Groups. *Social Psychiatry and Psychiatric Epidemiology*, 42, 14-23.

Judge, K., (1994). Serving children, siblings and spouse: Understanding the needs of other family members. In H. P. Lefley & M. Wasow (Eds.), *Helping Families Cope with Mental Illness* (pp.161-194). Newark, New Jersey: Harwood Academic.

Kwekkeboom, H. M. (2000). De zorg blijft. Verslag van een onderzoek onder familieleden en andere relaties van mensen met (langdurige) psychische problemen. (Research Report No. 62). Retrieved from Sociaal en Cultureel Planbureau website:
http://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2000/De_zorg_blijft

Larson, E. J., & Corrigan, P. W. (2008). The stigma of families with mental illness. *Academic Psychiatry*, 32(2), 87-91.

Lazarus R. S., & Folkman S. (1984). *Stress, appraisal, and coping*. New York: Springer.

Lefley, H. P. (1989). Family Burden and Family Stigma in Major Mental Illness, *American Psychologist*, 44(3), 556-560.

Markowitz, F. E. (1998). The Effects of Stigma on the Psychological Well-Being and Life Satisfaction of Persons with Mental Illness. *Journal of Health and Social Behavior*, 39, 335-348.

Miller, C. T., & Kaiser, C. R. (2001). A Theoretical Perspective on Coping with Stigma. *Journal of Social Issues*, 57(1), 73-92.

Miller, C. T., & Major, B. (2000). Coping with stigma and prejudice. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 243-272). New York: Guilford.

Neuberg, S. L., Smith, D. M., Hoffman, J. C., & Russell, F. J. (1994). When we observe stigmatized and "normal" individuals interacting: Stigma by association. *Personality and Social Psychology Bulletin*, 20, 196-209.

Östman, M., & Kjellin, L. (2002). Stigma by association, psychological factors in family members of people with mental illness. *British Journal of Psychiatry*, 181, 494-498.

Phelan, J. C., Bromet, E. J., & Link, B. G. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin*, 24, 115-126.

Platt, S. (1985). Measuring the burden of psychiatric illness on the family: An evaluation of some rating scales. *Psychology Medicine*, 15, 383-393.

Polit, D. F., & Beck, C. T. (2010). *Essentials of nursing research*. Philadelphia, PA: Wolters Kluwer Lippincott Williams & Wilkins.

- Pryor, J. B., Reeder, G. D., & Monroe, A. E. (2012). The infection of bad company: Stigma by association. *Journal of Personality and Social Psychology*, 102(2), 224-241.
- Rüsch, N., Corrigan, P. W., Powell, K., Rajah, A., Olschewski, M., Wilkniss, S., & Batia, K. (2009). A stress-coping model of mental illness stigma: II. Emotional stress responses, coping behavior and outcome. *Schizophrenia Research*, 110, 65-71.
- Sales, E. (2003). Family burden and quality of life. *Quality of Life Research*, 12, 33-41.
- Schene, A. H. (1990). Objective and subjective dimensions of family burden. *Social Psychiatry and Psychiatric Epidemiology*, 25(6), 289-297.
- Schene, A. H., Tessler, R. C. & Gamache, G. M. (1996). Caregiving in severe mental illness: conceptualization and measurement. In H. C. Knudsen & G. Thornicroft (Eds.) *Mental Health Service Evaluation* (pp. 296-316). Cambridge: Cambridge University Press.
- Seeman, M. V. (2013). Spotlight on sibling involvement in schizophrenia treatment. *Psychiatry*, 76(4), 311-22.
- Stutterheim, S. E. (2011). Understanding hiv-related stigma: Social and psychological processes (Doctoral dissertation). Retrieved from Maastricht University e-Library.
<http://arno.unimaas.nl/show.cgi?fid=21066>
- Thomas, D. R. (2006). A general inductive approach for qualitative data analysis. *American Journal of Evaluation*, 27(2), 237-246.
- Tsang, H. W. H., Tam, P. K. C., Chan, F., & Chang, W. M. (2003). Sources of burdens on families of individuals with mental illness. *International Journal of Rehabilitation Research*, 26(2), 123-130.
- Tuncay, T., Musabak, I., Gok, D. E., & Kutlu, M. (2008). The relationship between anxiety, coping strategies and characteristics of patients with diabetes. *Health and Quality of Life Outcomes*, (79), 1-9.
- Van der Sanden, R. L. M., Bos, A. E. R., Stutterheim, S. E., Pryor, J. B., & Kok, G. (2013). Experiences of Stigma by Association among Family Members of People with Mental Illness. *Rehabilitation Psychology*, 58(1), 73-80.
- Van der Sanden, R. L. M., Bos, A. E. R., Stutterheim, S. E., Kok, G., & Pryor, J. B. (2014). Stigma by Association as Experienced by Family Members of People with Mental Illness: A Qualitative Analysis. Manuscript submitted for publication.
- Van Erp, N., Place, C., & Michon, H. (2009). Familie in de langdurige GGz deel 2: Betrokkenheid in (F)ACT (Research Report No. AF0915). Retrieved from Trimbos Instituut website:
http://www.trimbos.nl/~media/Themas/4_Behandeling_reintegratie/Familie%20in%20de%20langdurige%20GGZ%20deel%201%20Interventies.ashx

Veit, C. T., & Ware, J. E. (1983). The structure of psychological distress and well-being in general populations. *Journal of Consulting and Clinical Psychology*, 51, 730-742.

Wahl, O. F. (1995). *Media madness: Public images of mental illness*. New Jersey: Rutgers University Press.

Werner, P., Mittelman, M., Goldstein, D., & Heinik, J. (2012). Family stigma and caregiver burden in Alzheimer's disease. *Gerontologist*, 52(1), 89-97.